In my world: developing empathy for difference

By Carole Lander

'Mummy, why is that man so short?'
'Because he didn't eat his vegetables when he was a kid.'

The short man who overheard this conversation was Jonathan Tripp. He was born with a condition of dwarfism. While he could see the funny side of the mother's reaction, it was just another incident in which an able-bodied, average-sized person found him amusing. This situation raises the question: how should children be introduced to the fact that some people are born and live with a disability? And how can parents and teachers develop empathy for them in the children under their charge?

I became immersed in the topic of dwarfism in 2012 when I wrote a book about it. *Little People Big Lives* is a non-fiction text that profiles 12 people who will never grow taller than 1.45 metres — the official definition of dwarfism as published by the World Health Organization (WHO). I attended a range of events and activities organised for and by short-statured people (as they are officially known in Australia) or little people as they are termed in the US and UK. Most of the people I interviewed loved sport of all kinds and their favourite way to participate was in events catering specifically for short-statured people.

When I watched the Melbourne basketball team (the sSpitfires) play against a team of adolescent boys, I was struck by the unfairness of this match. Because there are so few short-statured basketball players (only one in 20,000 babies are born with dwarfism) the only time they can complete against each other is in national and international sporting events. Try as I might, I could not put myself in their shoes. Empathy for someone whose life is very different to our own is difficult to conjure unless we spend considerable time and

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effort developing it. The motivation for writing my next book came from just such an endeavour. *In My World* contains two chapter books for children aged seven-plus. The main character in each story lives with a disability. I hope it will go some way to raising awareness and preventing the type of behaviour that, unfortunately, we have come to expect.

Jenny Zeuschner, parent of a five-year-old, is anticipating this. She told me: 'Lachie hasn't asked me why he is shorter than his classmates. He has no idea that he has a condition called dwarfism.' Yet, all too soon those classmates will realise Lachie is different and some of them will tease or even bully him.

Jenny and her husband had a huge shock when their son was born with this disability. Now, they are learning to live with it and she says:

> *Unfortunately there is a lack of awareness in society about short-statured conditions. Ignorance is a harsh word but it's true that there are people who show their ignorance. It's only a visual difference because cognitively a short-statured person can have a successful professional and vocational future.*

The same statement can be made about a child with any disability.

Stella Young is one of the people I interviewed for *Little People Big Lives*. With her condition of *osteogenesis imperfecta* (brittle bones), Stella was 88 centimetres in height, which qualified her as a short-statured person. However, Stella identified more specifically as a wheelchair user. For some years before she died in 2014, she was the go-to person for the Australian media when they wanted a spokesperson on disability and she was only too willing to speak out.

Discussing her 2014 show, *Tales from the Crip*, Stella Young told the Leader Press, 'Comedy is a great tool for social change — challenging prejudice and assumptions made about disabilities' (*Northcote Leader* 2014). She insisted that it was all right to laugh at her jokes but not at her. She was a very well adjusted young person who told me:

> *Everyone grows into their own special shape and size. Mine is small and different to most other people's, but I'm happy with this. And if I can make people laugh when I talk about my life then I'm happy with that too.*

Not all people with a disability or physical difference adjust as well as Young, particularly if they experience bullying and prejudice at school during that crucial period of life when character is being formed. In Australia we have legislation that can assist in a practical way. When a disabled child attends school, the principal is obliged by law to provide reasonable adjustments to allow the student to participate in activities alongside their peers. For example, footstools must be made available to allow a short-statured child to reach high benches. Wheelchair users must have access to ramps in order to come and go freely throughout the school.

These practicalities may ensure the child can participate fully in school life but the emotional experience of a child with a disability in the school environment is much harder to deal with. The Australian Curriculum takes this into consideration with two of its general capabilities — Ethical Understanding and Personal and Social Capability (ACARA 2008). The former:

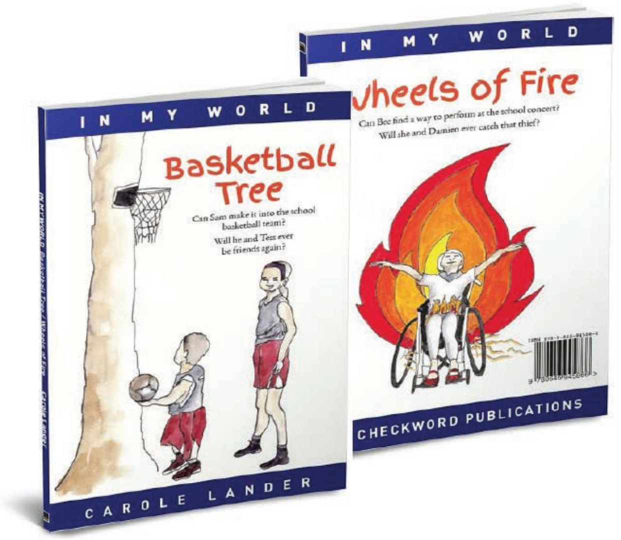
> *… involves students in building a strong personal and socially oriented ethical outlook that helps them to manage context, conflict and uncertainty, and to develop an awareness of the influence that their values and behaviour have on others.*

The Personal and Social Capability states that students:

> *… learn to understand themselves and others, and manage their relationships, lives, work and learning more effectively. Personal and social capability involves students in a range of practices including recognising and regulating emotions, developing empathy for others and understanding relationships, establishing and building positive relationships, making responsible decisions, working effectively in teams, handling challenging situations constructively and developing leadership skills.*

As teachers will know, these general capabilities are intended to cross all curriculum areas. They are addressed through the content of the learning areas. Yet, where are the resources that will help teachers to do this? A search of all the educational publishing companies' websites is frustrating. Since the introduction of the Australian Curriculum, the publishing houses have focused on the core curriculum subjects and little else. This is where my new book comes in, since it definitely fulfils the needs outlined in the two general capabilities above.

I was also motivated to write the two stories in *In My World* by the fact that during my interviews for *Little People Big Lives*, my subjects told me that they never saw themselves in the books they read at school. Indeed, Stella Young wrote in her letter 'To my eighty-year-old self':



> *You will write some fiction, in which the central character is a disabled teenage girl. Because f**k knows that wasn't around when you were growing up and desperately searching for characters you could truly relate to* (Hardy & McGuire 2014).

As mentioned, *In My World* contains two chapter book stories for primary-aged readers. Both of them have a main character who lives with a disability. In *Basketball Tree,* Sam is confronted by the fact that he's very short and may not fulfil his ambition to be a good basketball player. He also has to deal with bullying but at the school basketball tournament, he's the one who rescues the bully. In *Wheels of Fire,* Bec was born with muscular impairment and uses a wheelchair. Despite this, she wants to be like other kids in her class. When she discovers a way to dance alongside them on stage she realises she can be the same as well as different. She also finds her wheelchair very useful for catching the school thief.

In these stories, the heroes have adventures and achieve goals as they would in any novel for young readers. Their disability is referred to and dealt with incidentally. I know the reality of living with a disability can be far more challenging than these stories relay. The BBC 4 series *Born to be Different* is testament to that as it documents the lives of six families raising a disabled child, from birth to age 16. From the start, they all try to focus on the positive side of the challenges they face. When I interviewed the short-statured people for my non-fiction book, they also preferred to dwell on their achievements rather than the medical interventions they have to cope with.

Some parents and teachers might say my stories skim over the day-to-day challenges but I preferred to opt for positive disability representation and, reassuringly, I have received affirmative feedback. One parent, Katrina Reynolds, wrote to me:

> *I have a seven-year-old, Charlotte, who is average height and a three-year-old, Matilda, who has achondroplasia* [the most common cause of dwarfism/short stature]. *I started reading your new book to Charlotte last night and was brought to tears once I got to the chapter where it says that the boy having achondroplasia was a shock to his parents. I wanted to thank you for giving me a tool to teach other children about Matilda. The book is beautifully written and is making a big impact on Charlotte.*

I purposely downplayed many of the challenges so that children who have a disability can see themselves in scenarios where they win. As for the young readers who do not live with such differences, I believe that if they can read stories like these they are more likely to develop empathy for those living with a difference.

My efforts at finding a publisher for this book came to nothing. I was told they were a financial risk. That attitude is truly depressing and I am encouraged by librarians like Anette Ainsworth at Hale School, Perth, who wrote to me:

> *Everyone should be able to read books that are inclusive of children with disabilities. It is important to highlight how children who happen to have a disability live their lives and how cherished they are by those around them. Books are an avenue for children to understand disabilities. They allow children to understand their siblings, friends and peers.*

In the US, there is a growing movement called Disability in KidLit. Their website is dedicated to discussing the portrayal of disability in middle grade and young adult literature. They publish articles, reviews, interviews and discussions examining this topic from various angles — and always from the disabled perspective. The equivalent does not exist in Australia. Similarly, when researching the topic of autism for another story, I discovered that Scholastic US has published several non-fiction books on that topic and, for school-aged readers, they have the fiction *Same But Different: Different Teen Life on the Autism Express* by Holly Robinson Peete. When I asked a Melbourne Scholastic publisher about the lack of similar books in Australia, she sighed and referred to our small population. It is very frustrating to witness the lack of support from the main publishing houses that would have the capacity to promote books in a way that is beyond my capacity as a self-publisher. Admittedly, the population of the US does make it easier for a range of diverse books to be published and sold. The success of RJ Palacio's *Wonder* is an example; however, this is not a book for primary-aged children.

According to the WHO, over a billion people are estimated to live with some form of disability. This corresponds to about 15% of the world's population. Most of these children will go through the education system. In Australia, many will be integrated into regular schools where teachers need tools to encourage empathy among fellow students. *In My World* is my attempt to provide such a tool. I have spent my entire career in the education sector — as teacher, examiner, pre-service tutor — and now as a writer and editor. I sincerely hope *In My World* reaches the target audience: teachers and primary-aged students as well as parents and children reading at home.

Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination (WHO 2015). The same can be said about education: all children who live with a disability have a right to be educated in a fair, just environment where teachers and fellow students have empathy for their condition. Since becoming involved with people who live with a disability, I am now dedicated to see that come to fruition.

Copies of *In My World* are available at www.checkword.com.au OR www.intbooks.com.au

References

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